

PARKINSON

REPORT



NATIONAL
PARKINSON
FOUNDATION

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Aware in Care Campaign

Get the Kit. Know the Facts. Be *Aware in Care*.



Most of us know little about the dangers faced by people with Parkinson's disease during a hospital stay. But research shows that three out of four people with Parkinson's don't get their medication on time in the hospital. What's more, a recent study by NPF discovered that the vast majority of hospital staff don't know which drugs are unsafe for Parkinson's patients.

That's why NPF is launching a new awareness campaign called *Aware in Care*. This national initiative aims to make sure every person with Parkinson's gets the very best care possible during a hospital visit. This is important because people with Parkinson's are admitted to the hospital more frequently than their peers, have longer stays and experience more complications.

The *Aware in Care* kit is the centerpiece of this campaign. Each kit includes useful tools and information on how to prepare for a hospital stay—whether it's a planned visit or an emergency. This kit is free of charge and available to everyone with Parkinson's. Read on to learn more about the "10-Step Hospital Action Plan" included in the kit.

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**APRIL IS
PARKINSON'S
AWARENESS
MONTH**

**An Advocate for
the Parkinson's
Community**

"The *Aware in Care*
kit is a life-saver..."
...continued on pg 3

**Ways to Get
Involved with NPF**

Parkinson's
Awareness Month –
Give Hope Year-Round
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**Team Hope:
300 Perfect Jumps
for Parkinson's**

"Kevin Burkart
will take on the
challenge of 300
skydives in 1 day..."
...continued on pg 10

Generous support for *Aware in Care* has been provided by lead sponsor the Edmond J. Safra Philanthropic Foundation; the Eleanor M. and Herbert D. Katz Family Foundation; Novartis Pharmaceuticals Corporation; UCB; TEVA CNS; Abbott; and people like you.

10-STEP HOSPITAL ACTION PLAN

Your visit to the hospital should start long before you're even admitted.

1. Line up help. Make sure your Parkinson's care team includes a care partner, a neurologist, or movement disorders specialist, a primary care physician and a pharmacist.

2. Pack your *Aware in Care* Kit. Prepare your list of emergency contacts and medications—take the kit with you every time you go to the hospital.

3. Prepare for the unexpected. Always wear the Parkinson's Disease ID Bracelet and carry the Medical Alert Card included in the kit.

4. Find a good hospital. Contact local hospitals to determine which one will provide you with good Parkinson's care. Call ahead and ask questions.

5. Be vocal. During each hospital visit, explain to everyone on your medical team why you need your medications on time, every time.

6. Be persistent. Speak up if you don't feel your doctors or nurses are listening to your concerns.

7. Get moving. Soon after undergoing a medical procedure, ask to have a physical therapist show you how to build your physical skills and strength.

8. Stay on top of your care. Throughout your hospital stay, you and your loved ones should monitor your care closely.

9. Follow up. After you're discharged, make sure both your neurologist and primary care physician get a full report.

10. Connect with others. Contact your local NPF Chapter or support group for more information. Call NPF's Helpline at 1.800.4PD.INFO (473-4636).

Letter from the President



I'm often asked why is it that Parkinson's lacks the broad awareness of many other diseases. After all, it's now the 14th leading cause of death in the country.

The primary reason for this, in my view, is that the burden of having a progressive disorder for both the patient and care partner, particularly later in life, makes sustaining a highly organized volunteer leadership difficult. And without a group of strong local organizations all pulling together in the same direction, under a national umbrella, overall awareness suffers.

NPF has set about to change this. This year, we're organizing on a community level, building visibility and funding through our *Moving Day* walks—all 15 of them! With Katie Couric as honorary national chair, these walking events promise to raise much needed awareness on a local level as never before. But along with grand gestures, awareness is also created in small things.

Nationally, during the month of April, you can also help us move Parkinson's to center stage by wearing a Parkinson's awareness limited edition bracelet



featuring the message, "Move To Beat Parkinson's."

The wristband is free in April when you make a \$25 donation to NPF. It highlights the benefit of movement in combatting Parkinson's.

We believe that the time is now for Parkinson's to come into the light...to increase awareness, to develop more support services, better treatments and meaningful research that moves our community forward.

Thanks for your support,

Joyce Oberdorf
President and CEO

P.S. Check out other ways to get involved on page 8!